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Title: 'A little dollop of good in a very dark time': What organ donation meant to donor families

Objectives

1. To understand what organ donation meant to surviving relatives.
2. To elicit the tributes bereaved families' paid to their donors.

Method

This presentation is drawn from a qualitative interview study carried out with donating families to elicit their experiences of organ and tissue donation and the perceived influences on their decision making. Participants were recruited from targeted regions which included representation from 10 participating NHS Trusts. The study sample comprised 43 participants from 31 families. All participants were White British. Unusually for bereavement research, there was an equal number of men (n=21) and women (n=22). Participants were representative of a variety of family relationships. Participants were bereaved a mean of seven months at the time of recruitment to the study. Twelve families agreed to DBD and 18 families agreed to DCD. There were four cases of non-proceeding DCD and four DCD tissue donations only. The study was ethically approved.

Results

Through donation, participants felt that their relative's death had not been in vain and that their life had not been wasted. Non-proceeding DCD was described as a disappointment by some participants and pragmatically accepted by others. Motivations behind the decision to donate were reflected in statements such as making a difference in terms of improving someone's quality of life and life expectancy, enriching or extending the lives of others, creating, saving or giving life to someone else and relieving the suffering of other families. There was also evidence of reciprocity behind the decision to donate. Some participants described how receiving letters about the outcome of their relative's donation impacted their grief and bereavement. They felt sad and upset, yet pleased and happy. Their pleasure came from content in the letter that acknowledged the difference their relative had made to the lives of people. There was some evidence to suggest that families remained positive about the donation despite notification that the recipient had subsequently died. Motivations behind the decision to donate were reflected in statements such as making a difference in terms of improving someone's quality of life and life expectancy, enriching or extending the lives of others, creating, saving or giving life to someone else and relieving the suffering of other families.

Conclusion

No participant regretted the donation decision they made at the time of their relative's death. There was acceptance of the decision when carrying out their relatives' wishes. Participants described contrasting emotions when reading about the outcomes of donation and in particular, information about the transplant recipients. Some participants said they would agree to donation again.

